



Advancing methodology in the study of HIV status disclosure: The importance of considering disclosure target and intent



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ARTICLE INFO

Article history:

Received 7 October 2013

Received in revised form

17 February 2014

Accepted 27 February 2014

Available online 7 March 2014

Keywords:

PLWH

Tanzania

HIV disclosure

HIV-related stigma

Social support

Item response theory

Measurement

ABSTRACT

Disclosure of HIV status has been the focus of three decades of research, which have revealed its complex relations to many behaviors involved in HIV prevention and treatment, and exposed its central role in managing the HIV epidemic. The causes and consequences of disclosure acts have recently been the subject of several theoretical models. Although it is acknowledged that individual disclosure events are part of a broader process of disclosing one's HIV status to an increasing number of people, this process has received less theoretical attention. In quantitative studies of disclosure, researchers have often implicitly assumed that disclosure is a single unidimensional process appropriately measured via the total number of one's disclosure acts. However, there is also evidence that disclosure may have different causes and consequences depending on the types of actors involved (e.g. family members, friends) and on the presence or absence of the discloser's intention, suggesting that the unidimensionality assumption may not hold. We quantitatively examined the dimensionality of voluntary and involuntary disclosure to different categories of actors, using data collected via structured interviews in the spring of 2010 from 158 people living with HIV in Kilimanjaro, Tanzania. For voluntary disclosure, nonparametric item response analyses identified two multi-category clusters, family and community, and two single-category dimensions, partner and children. Involuntary disclosure consisted of several single- or two-category dimensions. Correlation analyses between the resulting disclosure dimensions and stigma and social support revealed distinct relationships for each disclosure dimension. Our results suggest that treating disclosure as a unidimensional construct is a simplification of disclosure processes that may lead to incorrect conclusions about disclosure correlates. We therefore recommend examining disclosure acts jointly to identify sample-specific dimensions before examining causes and consequences of disclosure. We propose a methodology for investigating disclosure processes, and recommend its adoption in future disclosure studies.

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1. Introduction

HIV-status disclosure can have a considerable impact on the psychological well-being of people living with HIV (PLWH) and on the prevention of HIV transmission, via behaviors such as HIV-

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testing, negotiating safe sex, involvement in medical care, breast feeding (Chaudoir et al., 2011; Klitzman et al., 2004; Nachega et al., 2012; Stutterheim et al., 2011a; Wohl et al., 2011). Many studies have examined the causes and consequences of disclosure in PLWH (e.g., Chandra et al., 2003; Chaudoir and Fisher, 2010; Pachankis, 2007; Sandelowski et al., 2004). Some studies suggest that disclosing one's HIV status can have beneficial effects such as increased social support, decreased experienced stigma, improved treatment adherence, greater well-being, and healthier behaviors (Peretti-Watel et al., 2006; Skogmar et al., 2006; Smith et al., 2008). Other studies point out that disclosure may also result in stigmatization (Stutterheim et al., 2011a; Valle and Levy, 2009) manifest as, for example, avoidance, rejection, exclusion, blaming, physical

distance, and awkward social interaction (Shamos et al., 2009; Stutterheim et al., 2009, 2012). High levels of perceived, anticipated, or internalized stigma, in turn, have been found to yield lower levels of disclosure (Stutterheim et al., 2011b; Tsai et al., 2013; Wolitski et al., 2009). Recent reviews of HIV disclosure research describe a complex and often inconsistent picture of the relationships between disclosure acts, antecedents and outcomes (Chaudoir and Fisher, 2010; Chaudoir et al., 2011; Smith et al., 2008). Clarifying these relationships is essential for the development of successful interventions to reduce stigma, enhance social support, maintain mental and physical health, promote healthy behaviors, and thereby improve the general well-being of PLWH, and lower the risk of HIV transmission (Chaudoir et al., 2011).

One strategy to accelerate progress in this research area is to refocus on fundamental aspects of how we operationalize, measure, and analyze disclosure quantitatively. There has been renewed interest recently in advancing conceptual and measurement clarity. Several reviewers highlighted the need for improved measurement (e.g. Obermeyer et al., 2011; Smith et al., 2008), and several authors proposed models to guide research on disclosure (Bairan et al., 2007; Bird and Voisin, 2011; Chaudoir and Fisher, 2010; Chaudoir et al., 2011; Mayfield Arnold et al., 2008; Serovich et al., 2008) and stigma (Bos et al., 2013; Earnshaw and Chaudoir, 2009; Mahajan et al., 2008). However, although most research has focused on the broader process of increasing one's disclosure levels from none or few confidants to the entire social network, the existing theoretical models interpreted all empirical evidence in terms of causes and consequences of single disclosure events. This interpretation may not be fully warranted, as individual events may well have different effects on relevant outcomes compared to overall assessments of one's degree of disclosure regarding one's identity (Chaudoir and Fisher, 2010). To further improve conceptual clarity, it is therefore necessary to distinguish between these two conceptualizations of disclosure, i.e. event versus process, and, in addition, to direct theoretical and methodological efforts towards the disclosure process.

Disclosure is often implicitly conceptualized as a single gradual process of sharing information about one's HIV status to an increasing number of people, but evidence is accumulating that this is not a uniform process (Obermeyer et al., 2011). Thus, examining the possible dimensions of disclosure may lead to its better conceptualization and measurement. Within the existing literature, two factors stand out as potential sources of multi-dimensionality: the types of actors involved as disclosure targets, and the discloser's intention. While their influence is commonly overlooked, several studies suggest that considering these factors may be relevant for understanding the dynamics of HIV-status disclosure.

Quantitative studies examining predictors or consequences of disclosure often include several disclosure targets in their assessment tool and ask people to select to whom they have disclosed from a list of actor categories (e.g. Emlet, 2006; Skogmar et al., 2006). However, a common analytical choice is to add up positive answers to obtain a total score representing the extent of disclosure (e.g., Armistead et al., 1999; Emlet, 2006; Wohl et al., 2011), or merge them into a dichotomous variable assessing whether the person disclosed to no one versus to at least one person (Nachega et al., 2012; Wohl et al., 2011). This method does not allow for an examination of dimensionality, as computing a total score or a dichotomous variable implicitly assumes that disclosure acts involving various actors are interchangeable indicators of a single disclosure process. This assumption might not hold, as several studies, both qualitative and quantitative, indicate that each act of disclosure to a particular type of actor may have different causes and consequences. For example, disclosure to a partner may be intended to prevent HIV transmission and to gain social support in

the context of a steady relationship, disclosing to a family member may aim for emotional or financial support, while disclosing to a broader audience may be motivated by a wish to change the perception of PLWH by the community at large (Greeff et al., 2008; Sowell et al., 2003; Stutterheim et al., 2011b; Vu et al., 2012). Hence, other authors chose to analyze disclosure acts to different actor categories separately (Armistead et al., 1999; Tsai et al., 2013). However, this choice assumes that disclosure acts are independent of each other, which goes against existing evidence that suggests single disclosure events are likely to influence the likelihood of subsequent disclosure (Chaudoir and Fisher, 2010; Chaudoir et al., 2011). Between unidimensionality and independence lays a third analytical choice (so far unexplored): to conceptualize HIV disclosure as a multi-dimensional phenomenon consisting of several clusters of related disclosure events involving different types of actors. Adopting any of these three choices based on theoretical arguments alone may lead to erroneous conclusions if the approach selected does not match the dynamics of HIV disclosure in the target population. Fortunately, this decision can also be informed by a psychometric analysis of participants' reports regarding disclosure to a range of actor categories. By performing such analysis, researchers would be able to adapt the conceptualization of HIV disclosure to the population under study, and thus build a more valid basis for examining the causes and consequences of disclosure taking into account the type of actors. No empirical investigations of HIV disclosure have adopted this approach to date.

Similarly to the role of disclosure target, the influence of the discloser's intention on HIV-status disclosure has been scarcely explored. Assessment tools rarely inquire as to whether disclosure acts were voluntary or involuntary, but simply ask about their occurrence thereby implicitly assuming that intention has a negligible impact. Yet, the causes and consequences of disclosure acts may vary substantially depending on whether they occur as an intentional and planned activity or without one's intent. In the first case, the discloser maintains control over the decision to disclose and/or aspects of the event itself such as the content and timing (Chandra et al., 2003; Chaudoir et al., 2011; Sandelowski et al., 2004), and the event may be beneficial particularly if motivated by approach-focused goals (Chaudoir and Fisher, 2010). In the second case, for example when others infer one's HIV status from visible physical symptoms or seeing a person enter an HIV clinic, or when the information is disclosed without one's consent by another person, disclosure may have particularly harmful consequences such as increased stigma (Obermeyer et al., 2011; Sandelowski et al., 2004). Although several qualitative studies have made the distinction between voluntary disclosure versus disclosure without consent (Chandra et al., 2003), managed versus mismanaged (Sandelowski et al., 2004), or voluntary versus involuntary disclosure (Varga et al., 2006), we have not found any quantitative studies that have examined them as separate dimensions. In light of these qualitative findings, assessing voluntary and involuntary HIV disclosure separately may open new possibilities for investigating HIV disclosure processes in terms of both dimensionality and relationships with relevant concepts.

In sum, disclosure is a central topic in HIV-related research, and many studies have revealed its relation to numerous concepts relevant for PLWH, such as perceived stigma, social support, psychological well-being, treatment adherence, and safe sexual practices. In line with the recent focus on refining conceptualization and measurement of disclosure, the present study aimed to, firstly, examine empirically the structure of disclosure as a process with a focus on two potential influences (the types of disclosure targets, and the discloser's intention), and, secondly, compare this new approach to disclosure analyses to the commonly used cumulative score in the exploration of the relationship between disclosure and

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